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ILLINOIS. COMMISSION FOR HANDICAPPED  
CHILDREN

THE EPILEPTIC CHILD IN ILLINOIS 1943

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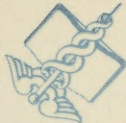


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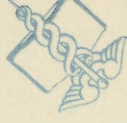
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LAWRENCE J. LINCK  
*Executive Director*

211 West Wacker Drive  
Chicago



Pamphlet

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## FOREWORD

Among the duties charged to the Illinois Commission for Handicapped Children by the General Assembly is the promotion of special classes and competent individual instruction, adequate provisions for medical diagnosis and treatment, vocational training and placement, and social adjustment for all types of handicapped children in all parts of the State.

The publication of this pamphlet is an attempt on the part of the Commission partially to fulfill that responsibility in respect to one group of handicapped children — those who are suffering from convulsive disorders and who are generally known as epileptic. It is an attempt briefly to set forth answers to some of the questions basic to action—What is epilepsy? How many epileptic children are there in Illinois? What is now being done and what needs to be done to relieve their condition and to equip them to lead lives as nearly normal as possible?

The material set forth is directed toward a greater public understanding of the problems of these children. It is in no way intended as a technical study for medical specialists concerned with convulsive disorders.

To Douglas Buchanan, M.D., of the University of Chicago, we extend our thanks for giving so generously of his time and advice. Responsibility for inadequacies in this paper rests with the Commission staff, however, not with Doctor Buchanan.

Acknowledgment is also made to Miss Eveline E. Blumenthal, Social Research Analyst of our staff, who did the research and prepared the manuscript for this study.

As it does with respect to its entire program, the Commission welcomes constructive criticism and comment on this publication.

LAWRENCE J. LINCK  
Executive Director





## INTRODUCTION

Convulsive seizures are one of the oldest of known human disorders. In ancient times those afflicted were thought to have been possessed by demons, and were shunned with horror. Until the last century, these unfortunates were subjected to every imaginable type of treatment, varying from the practice of boring holes in their skulls to permit "evil spirits" to escape, to use of the most unpalatable so-called curatives. It has been observed that "in fact, there is not a substance in the world, capable of passing through the gullet of man, that has not at one time or other enjoyed a reputation of being an anti-epileptic."<sup>1</sup> Remedies included such prescriptions as swallowing twenty-one houseflies in a liquid medium; solution of burnt pig's bones; claws of a lynx; nail parings; ashes of a pulverized toad; vulture liver; mummy dust; and many other such concoctions.<sup>2</sup> Throughout history, human blood was deemed to be especially efficacious, and sufferers from convulsions habitually frequented the battleground of dying gladiators and the execution places of persons condemned to die by the guillotine or the ax, to fight for the privilege of drinking fresh human blood.

With such a background of superstition, horror, and ignorance, it is little wonder that a stigma was attached to the disorder which has lasted up to the present day.

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<sup>1</sup> Quoted from Sieveking by Leo Kanner in "The Folklore and Cultural History of Epilepsy," *Med. Life*, 37 (April, 1930), 181.

<sup>2</sup> *Ibid.*, pp. 181 ff.





## DEFINITION OF THE PROBLEM

In the last two decades, older concepts of the nature and origin of these paroxysms have crumbled under the discoveries and contributions of neuropathologists, neuro-surgeons, biochemists, physiologists, and physicians, who now consider these seizures to be not a *disease*, but a symptom of underlying pathology. Convulsive seizures are so infinitely variable in character and incidence and generally so hidden in origin that they have defied attempts at definition. Because of this, the name "epilepsy" is considered by many authorities to be an inaccurate and undesirable term. It has been suggested that "paroxysmal disorders," "convulsive state," or "convulsive seizures," be used instead.

There are two generally recognized forms of attack, with rather well defined clinical symptoms: major seizures and minor seizures. The variations in type and combinations of symptoms are so great that no attempt will be made here to include a complete description.<sup>1</sup>

Major seizures are characterized by sudden and complete loss of consciousness and severe convulsions which consist of powerful muscular spasms which are at first rigid and then clonic, or shock-like in character. A post-seizure period of heavy sleep usually follows. In approximately 50 per cent of the cases, an aura, or warning, precedes the seizure, and there may be outward symptoms or signs occurring hours or days be-

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<sup>1</sup> A classic discussion of the nature and symptoms of paroxysmal disorders may be found in S. A. Kinnier Wilson's *Neurology*, ed. by A. Ninian Bruce (Baltimore: Williams & Wilkins, 1940), II, 1469-1544, chap. 26, "The Epilepsies."

fore the onset of the spasm. The seizure itself may last for only a few minutes or for a half-hour or longer. Headaches, vomiting, or muscle soreness may follow.

Minor seizures consist of transient episodes of unconsciousness, with convulsive movements, if any, usually confined to slight twitching of the face or eyelids, or to a nodding movement of the head. According to Merritt, the "degree of loss of consciousness may vary from a complete amnesia for a minute or more to a second of partial retardation of activity of higher cerebral centers which can be detected only by special methods."<sup>1</sup> It is because of the frequent absence of outward symptoms and the rapid regaining of the faculties that minor seizures are often unrecognized as convulsions. A blank stare, a slight swaying of the body, cessation of conversation, or relaxation of the grip may be the only outward sign. Such attacks are often described as "thinking spells" in children. Although this transient mental absence may be so fleeting in itself that it is undetected, a prolonged state of confusion may follow. According to Wilson,

symptoms may ensue whose complexity or length is altogether disproportionate to the preceding functional disorder. The importance of this cannot be stressed too much, for the true character of minor fits is often not realized until a major attack takes place or unless recurring peculiarities of behavior on the patient's part compel attention.<sup>2</sup>

Minor seizures are more commonly seen in childhood than in later life, and occur with much greater frequency than do major convulsions.

In summary, to quote Cobb and Lennox, convulsive fits

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<sup>1</sup> H. Houston Merritt, "The Treatment of Epilepsy," *Med. Clin. of N. A.*, XXV (Philadelphia, W. B. Saunders Co., September, 1941), p. 1332.

<sup>2</sup> Wilson, *op. cit.*, pp. 1485-86.

consist of the sudden and repeated appearance of seizures, of which disturbances of consciousness, convulsive movements, or both are the principal element. The term seizure covers various manifestations, which patients may exhibit; convulsions . . . , transient losses of consciousness . . . , periods of mental confusion, dreamy states, dizziness, or the performance of automatic acts of which the patient afterwards has no recollection (equivalent with amnesia) are some of the more usual types, but the symptomatology is infinitely variable. In general, any patient who has recurrent seizures is called epileptic.<sup>1</sup>

No feature is constant, according to Wilson, the least mutable being "sudden onset, brief duration, and recurring habit."<sup>2</sup>

A simple and descriptive clinical definition is that offered by Merritt, who says, "Epilepsy is a term used to describe a wide variety of abnormalities of consciousness with or without convulsive movements."<sup>3</sup>

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<sup>1</sup> Stanley Cobb and Wm. G. Lennox, "Epilepsy," *Diseases of the Nervous System, Oxford Medicine*, VI (New York: Oxford University Press, 1941), p. 893-4.

<sup>2</sup> Wilson, *op. cit.*, p. 1470.

<sup>3</sup> Merritt, *op. cit.*, p. 1331.



## SOCIAL AND ECONOMIC IMPLICATIONS

Because of the unfortunate and unnecessary stigma attached to the convulsive disorders, social implications of the problem are immeasurably increased, and the implementation of any treatment program made much more difficult. Persons so handicapped are shunned and excluded from participation in community life and frequently are prevented from attending school regularly. They are advised not to marry for fear of transmitting their disability to their children.<sup>1</sup> Vocational opportunities are limited, because of the necessity of avoiding hazardous situations and because most employers will not accept them because of employer-liability in case of injury while at work.

The cost to society is heavy. There are approximately 30,000 epileptics in various state institutions in the forty-eight states.<sup>2</sup> But even greater than the institutional cost is the economic loss with respect to the large majority who are not receiving institutional care. Because a large proportion of these are reduced to economic unproductivity, the total direct annual cost has been estimated by one authority to reach an aggregate of \$100,000,000.<sup>3</sup>

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<sup>1</sup> According to studies made at the Harvard University Medical School, "the hereditary factor, although not as great as is popularly supposed, is important. . . . Much confusion of thought has resulted from a tendency to consider only persons with an actual defect and to disregard the far greater numbers of carriers of this defect. It would seem that epilepsy is hereditary in the same manner as other morbid conditions, for example, cancer or kidney disease. The 'constitution' or susceptibility is present in all who develop the condition, but whether seizures actually appear may depend on fortuitous contributing causes. The susceptibility may be so strong in one individual that little or no apparent cause is needed to 'set off' an attack, or so weak in another that attacks begin only after severe stimuli. The most important associated causes are injuries to the central nervous system." (Cobb and Lennox, *op. cit.*, pp. 902-903.)

<sup>2</sup> Albert Deutsch, *The Mentally Ill in America* (New York: Doubleday, Doran & Co., 1938), p. 383.

<sup>3</sup> Wm. G. Lennox, *Science and Seizures* (New York: Harper Bros., 1941), p. 56.

Much has been written about the "epileptic personality" which has been discredited in the light of modern studies of mental, emotional, and personality growth. Convulsions, like any other disability tending to isolate an individual or make him dependent or conspicuous, will react unfavorably on personality development. Suffering ostracism both socially and vocationally, he may become self-conscious and discouraged. Anxiety, based on fear of seizures, may increase his lack of adjustment. It has been stated that the egoism, instability and hypochondriasis commonly attributed to those having convulsive seizures are symptoms to be found in any chronic invalid, and "may be the results of invalidism and discouragement."<sup>1</sup>

With the exception of mental defectives and those whose handicaps were caused by injury or disease of the central nervous system, there is no specific group of the physically or mentally handicapped in which more persons having convulsive seizures may be found than in the general population.

Because most of the statistical information which has been released on seizures has been based on research among institutional patients, it is unreliable when applied to extra-mural patients. The general belief that mental deterioration inevitably results from convulsive attacks can be disproved. Lennox, speaking from the viewpoint of statistics on almost 2,000 extra-institutional patients, states that although congenital mental defect and heredity of seizures are linked, and twice as many mental defectives have seizures as do mentally normal persons,<sup>2</sup> yet the great

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<sup>1</sup> Cobb and Lennox, *op. cit.*, p. 900.

<sup>2</sup> Lennox, *op. cit.*, p. 51.

majority suffer no mental impairment. For instance, of 1,905 patients on whom information had been secured from neurologists throughout the country, 2 per cent were superior mentally, 62 per cent were normal, 22 per cent were slightly subnormal, 12 per cent definitely deteriorated, and 2 per cent markedly deteriorated.<sup>1</sup> Of those considered mentally normal at birth, 75.4 per cent were mentally normal, and an approximately equal percentage (76.4) of those who had suffered no cerebral trauma prior to the onset of seizures, were normal. The average patient in this group had had 2,000 seizures over a period of eight years.<sup>2</sup> These data compare favorably with the White House Conference estimates of 1 per cent markedly defective and 14 per cent subnormal in the general population.<sup>3</sup>

Sullivan and Gahagan, in a study of 103 children admitted to the Los Angeles Children's Hospital for treatment for convulsions, found that 24.2 per cent were borderline or feeble-minded (having an I.Q. below 90), as against a percentage of 15.7 for the Los Angeles City Schools.<sup>4</sup>

It may be seen, then, that mental deterioration in this disorder is greatly overemphasized. In general, mental impairment may be due to any of the following causes: (1) congenital defect; (2) cerebral trauma; (3) great frequency of attacks; (4) uncontrolled medical treatment, which is especially danger-

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<sup>1</sup> William G. Lennox, "Mental Defect in Epilepsy and the Influence of Heredity," *Am. J. Psychiat.*, 98 (March, 1942), 734.

<sup>2</sup> *Ibid.*, p. 735.

<sup>3</sup> *White House Conference on Child Health and Protection*, Section III. *The Handicapped: Prevention, Maintenance, Protection* (New York: Century Co., 1933), p. 334.

<sup>4</sup> Ellen B. Sullivan and Lawrence Gahagan, "On Intelligence of Epileptic Children," *Gen. Psych. Monographs*, 17 (October, 1935), 337.



ous when purchased by mail; and (5) discouragement, resignation, and lack of initiative.<sup>1</sup>

The fact of living under constant threat of convulsions is manifestly a heavy psychologic burden. It is apt to result in emotional tensions and to lead to a feeling of hopelessness which tinges intellectual processes and renders concentration difficult. . . . If myriads of brief "absences" of consciousness occur several times over substantial periods, their effect may be crippling to any complicated form of mental activity.<sup>2</sup>

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<sup>1</sup>Lennox, *Science and Seizures*, p. 51.

<sup>2</sup>J. Putnam Tracy and H. Houston Merritt, "Dullness as an Epileptic Equivalent," *Arch. Neur. and Psychiat.*, 45 (May, 1941), 798.

## EXTENT OF THE PROBLEM

No general census of the number of persons having seizures is available either for the United States or any other country. Because of the very nature of the problem, it does not lend itself readily to statistical study. Its occurrence is many times concealed for fear of social stigma. A large number suffering from the disorder do not seek medical treatment because of their belief that they are incurable. Or, the seizures may be so fleeting or mild in nature that their true nature remains unrecognized. For these reasons, most estimates made as to the extent of incidence of convulsive seizures are much too low.

During the first World War, examinations given to 2,500,000 men provided a basis for the first extensive estimate. Since diagnosis was made upon the basis of a volunteered history of childhood convulsions, however, cases in which this was unknown or concealed were not included and the disorder became apparent only when a seizure occurred after induction into service. Of the total number, 5.15 per 1,000 gave such histories. Admissions to sick reports because of seizures after entrance into service were 2.09 per 1,000 for whites and 7.23 for colored in 1918, and 2.70 for whites and 6.54 for colored in 1917. Total admissions to sick reports in 1917 for the United States, Europe, and all other countries were 2.70 for whites and 5.23 for colored.<sup>1</sup>

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<sup>1</sup> Quoted from reports of the Surgeon General of the U. S. Army, by Charles B. Davenport, "Racial and Geographical Distribution of Epilepsy," *Epilepsy and the Convulsive State*, Vol. VII of Research Publications of The Association for Research in Nervous and Mental Diseases (Baltimore: Williams & Wilkins, 1931), p. 121. These racial differences have not been borne out in further research.

Because convulsive seizures are predominantly a disorder of childhood and adolescence, the rate of 5.15 per 1,000 for drafted men is too low for valid application to the child population of the country. Almost one-half of all persons admitted to institutions for convulsions are under twenty. The White House Conference report, recognizing the difficulty of proper weighting, nevertheless proposes an estimate of 8.0 or 9.0 per 1,000 for the total population under twenty,<sup>1</sup> which, on the basis of the 1940 census would mean that there were between 380,000 and 430,000 epileptics in this age group in the United States.

Although great regional variations in the draft figures led to doubts as to their validity, the estimate has been corroborated in subsequent studies elsewhere. In an inquiry into the histories of 1,000 medical students and nurses conducted by Lennox of Harvard University Medical School, a rate of 5 per 1,000 was discovered, 1 out of every 200 having a history of seizures in their families.<sup>2</sup> This, he notes, is approximately the same number as those having active tuberculosis or diabetes.

A house-to-house canvass conducted as part of the Texas Child Welfare Survey disclosed a rate of 2 per 1,000 among children less than nineteen years of age,<sup>3</sup> a figure identical with that estimated by the Board of Education of the City of New York in 1936,<sup>4</sup> and that resulting from an extensive study of nine northern Michigan counties in 1933, covering a population of 73,056.<sup>5</sup> Closely approximating these is the estimate of 2.29 per 1,000 estimated in a study

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<sup>1</sup> *White House Conference on Child Health and Protection*, op. cit., p. 292.

<sup>2</sup> Lennox, *Science and Seizures*, p. 21.

<sup>3</sup> *Texas' Children*, The Report of the Texas Child Welfare Survey, University of Texas Publication 3837 (Austin: Univ. of Texas, 1938), p. 76.

<sup>4</sup> *Epileptic Children*, Board of Education, The City of New York, Committee for the Study of Care and Education of Physically Handicapped Children in the Public Schools of the City of New York (New York: Board of Education, 1941), p. 35.

<sup>5</sup> C. L. Anderson, "Epilepsy in the State of Michigan," *Ment. Hyg.*, 20 (July, 1936), 458.

of the incidence of convulsive seizures in the Eastern Health District of Baltimore in 1936, covering a population of 55,000. In this study, all doubtful cases were excluded.<sup>1</sup>

Undoubtedly, in all of these cases, the inclusion of unrecognized or marginal types of seizures would make the rate higher. As the New York report stated: "It is not necessary to demonstrate by statistics the well-known tendency of people to minimize symptoms or disability if knowledge of them were to result in deprivation of privileges or to be contrary to their interests."<sup>2</sup>

The only inquiry directed toward discovery of the extent of the problem in Illinois was the cursory survey made by senatorial districts in 1912 by the Committee of Fifty. This committee, formed for the purpose of securing establishment of a colony for this group of handicapped in Illinois, estimated that one out of every 500 was subject to seizures,<sup>3</sup> observing that this was a conservative estimate and undoubtedly an under-statement of the real seriousness of the problem. The estimate does agree, however, with those given in the other studies cited.

Thus, since the 1940 Federal census lists, 1,968,335 children in Illinois between the ages of five and twenty-one, estimates as to the number having seizures would range from 4,000 according to the lowest rate (2 per 1,000) to 18,000 on the basis of the highest rate (9 per 1,000).

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<sup>1</sup> Paul Lemkau, Christopher Tietze, and Marcia Cooper, "Mental Hygiene Problems in an Urban District," *Ment. Hyg.*, 26, (April, 1942), 280.

<sup>2</sup> *Epileptic Children*, pp. 35-36.

<sup>3</sup> *How the Uncared-for Epileptic Fares in Illinois*. Report of the Committee of 50 (1912), p. 28.



## *A STATE PROGRAM FOR CHILDREN WITH CONVULSIVE SEIZURES*

A state program designed to meet the medical, social, and educational problems of the child subject to seizures would, in light of the picture here presented, involve three major phases: (1) treatment, (2) public education, and (3) research. The treatment program, although inseparable from the other two phases, would have the following significant factors: identification and diagnosis, medical supervision and treatment, colony and nursing-home care, aftercare, educational provisions, and vocational guidance, training, and placement.

**Identification and diagnosis** Thousands of dollars could be saved annually by the State if an effective program of early case-finding and treatment were established. This would depend upon the earnest coordination of the facilities of all schools, health and welfare agencies, county physicians' organizations, public health services, children's agencies, and parents and relatives. Thus the program would be inextricably bound up with that of public education, to create a realization of the extreme urgency of recognizing the disorder early in life and having treatment instituted at the earliest possible moment. This is important not only with respect to remedial efforts medically, but also to prevent development of personality difficulties. The importance of early diagnosis cannot be stressed too greatly, since authorities agree that chronic convulsions are frequently the result of habit formation, through repetition of the seizures and weakening of resistance. Gowers has called it a

“self-perpetuating” disorder.<sup>1</sup> Parents who believe that children will “outgrow” convulsions or seizures are only furthering the gravity of the disorder by waiting until some abnormality appears before starting treatment. As Thom says:

There seems to be little doubt in the minds of those most interested in the subject of epilepsy that each convulsion paves the way for the succeeding one and that the path becomes deeper and the demarcation sharper and more easily traversed. . . . For this reason it is tremendously important for the future welfare of the child that every investigation be made, by both clinical examination and laboratory tests, to determine the exciting factor in the production of these infantile convulsions.<sup>2</sup>

Especially important is early recognition and treatment of minor seizures, which are so often overlooked, but which may be present for years before an overt convulsion occurs. From 70 to 80 per cent of cases show the onset before the age of twenty, according to varying estimates, the two most dangerous periods being the first two years of life and the adolescent period.<sup>3</sup>

Finally, early diagnosis is essential in cases in which the seizures are precipitated by brain injury, brain tumor, or other lesions which might possibly be remedied by surgery.

**Medical supervision and treatment** No state has a program for treatment of persons suffering from convulsive seizures whose condition is not so serious as to require custodial care. Only ten states have special institutions or colonies.<sup>4</sup> Of the 30,000 who are

<sup>1</sup>L. J. J. Muskens, *Epilepsy: Comparative Pathogenesis, Symptoms, Treatment* (New York: Wm. Wood & Co., 1928), p. 335.

<sup>2</sup>Study by Pigott, Weingrow and Fitch, quoted by Douglas A. Thom, “Convulsions of Early Life and Their Relation to the Chronic Convulsive Disorders and Mental Defect,” *Am. J. Psychiat.*, 98 (January, 1942), 573.

<sup>3</sup>Lennox, *Science and Seizures*, p. 38.

<sup>4</sup>These are: Indiana, Kansas, Massachusetts, Michigan, Minnesota, New Jersey, New York, Ohio, Pennsylvania, and Texas. (*Hospital Service in the United States, 1943*, reprint of *J. Amer. Med. Assn.*, March 27, 1943.) Institutionalization will not be fully discussed here, since this survey is directed mainly toward care of those who are adjustable to community life. In general, commitment is recommended only in cases of severe mental deterioration; if attacks are frequent and violent and uncontrollable by medication; if constant attention is required, or the welfare of other members of the family otherwise jeopardized.

now institutionalized, only one-third are in special hospitals. The remainder are housed in various state and private institutions for the mentally diseased and the mentally defective, or penal and correctional institutions. This general lack of a definite program and tendency to use any and all facilities available has produced a chaotic situation, and has furthered the stigma with which the disorder is associated. An adequate program of medical care would envision three types of service: hospital care, home care, and custodial care, all based upon continuing and intensive research. According to Shou, about 50 per cent of those having convulsions can become wholly or partially free from seizures with hospital treatment.<sup>1</sup>

Aftercare of patients should be in colonies for those who do not respond to treatment, and in nursing-homes for those who need further hospital care or who need close supervision because of frequent or severe seizures. A family placement program is an essential resource for those whose return to the environment from which they came would be damaging. Follow-up service, both with respect to medical care and social adjustment, is vital, in order that the physician have assurance that his recommendations are being followed carefully, and the family and child given the benefit of guidance in educational, recreational, and vocational planning.

Outpatient centers established throughout the state would serve many urgent needs, such as supervising the training of children who have convulsions and are mentally normal, instructing persons having the care of those living at home, training field workers, and stimulating the interest of lay and professional

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<sup>1</sup>H. I. Shou, "The Ideal Organization of the Treatment and Care of Epileptics," *Epilepsia*, 2nd ser. I (May, 1938), 99.

persons who would be instrumental in effectively interpreting the nature of the disorder to the public.

Two European countries, Holland and Denmark, have had excellent systems of care. Holland had two large central hospitals and a third under construction at the time of the Nazi invasion. In addition, ten consultation offices and three polyclinics were established in different parts of the country, staffed by central hospital doctors, who supervised former patients and admitted new ones. Two institutes for treatment were maintained, and two special schools for mentally normal children excluded from regular schools because of seizures. A visiting nurse system was in operation for aftercare. One of the chief features of the program was a nation-wide propaganda association, with a membership of 100,000 persons, the income from their dues providing for the care of indigent patients, and for the promotion of public education. Branches of this association were established in every town in Holland.<sup>1</sup>

Denmark had a central hospital solely for adults, with an elaborately equipped laboratory for research. Different types of cases were segregated and special wards maintained for those who were psychotic. In addition, there was a special hospital for children between the ages of one and fifteen, with facilities for segregating new from chronic cases. Only children of normal mentality were accepted. Affiliated with the children's hospital were two homes, one for boys and one for girls, where they received schooling while under treatment. Family care was provided for those patients for whom it was recommended, through arrangements between the hospitals and 150 private

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<sup>1</sup>B. Ch. Ledeboor, "Care for Epileptics in Holland," *Epilepsia*, 2nd ser. 1 (April, 1940), 268-80; see also H. I. Schou, "Institutional Care of Epileptics in Different Countries of the World," *Ibid.*, pp. 252-60.



families who co-operated in the treatment program. Nursing homes were established throughout the country, affiliated with the hospital. The Danish system was entirely state-supported, with the exception of the hospitals, which were private.<sup>1</sup>

Therapy in convulsive disorders is based upon medical treatment, supplemented by every possible means to promote the physical and mental hygiene of the patient, through diet control, moderate exercise, good posture and circulation, and avoidance of emotional strain. Operations for removal of adhesions, scar tissue, tumors, etc., when indicated, are effective in cessation of seizures in only one-half of the cases in which they are resorted to.<sup>2</sup> No medicine is specific as a curative, but three are now in general use for control for seizures — diphenol hydantoin (Dilantin), phenobarbital (Luminal), and bromide. Dangerous toxic effects may result from the misuse of each of them, necessitating careful supervision by competent physicians in their prescription. Dilantin, introduced by Putnam and Merritt of Boston in 1938, has proved remarkably effective, bringing complete relief from seizures in approximately 50 per cent of cases, and a marked reduction of symptoms in many more,<sup>3</sup> in addition to effecting a marked increase in mental alertness and clarity.

Advertised cures are especially dangerous, since there is no means to prescribe the correct medicine or the proper dosage, or to determine possible idiosyncrasy by the individual to the given treatment.

The lay person, in handling a child during a paroxysm, can do little except to loosen tight clothing, taking steps to prevent physical injury, and plac-

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<sup>1</sup> H. I. Schou, "The Ideal Organization, etc." *op. cit.*, pp. 102 ff.

<sup>2</sup> Wilder Penfield and Theodore C. Erickson, *Epilepsy and Cerebral Localization* (Baltimore: Charles C. Thomas, 1941).

<sup>3</sup> Merritt, "The Treatment of Epilepsy," *op. cit.*, pp. 1331-46.

ing a semi-hard object between the teeth to prevent tongue biting. The child should be permitted to sleep after the spasm has run its course.

**Educational provisions** The average child subject to seizures is not in need of special educational provisions, and if mentally normal, should take his place in regular classes, if his seizures are not so frequent and severe as to disrupt the classroom or incapacitate him from learning, or if he is not too much of a behavior problem. Since from 60 to 80 per cent of epileptics are considered to be mentally normal, adequate educational provisions assume great importance in light of the fact that stimulation of intellectual interests is a major phase of any treatment program. If the child is mentally retarded, placement in an ungraded class may be necessary. Otherwise, only slight modification of the curriculum is required. Michigan is the only state allocating funds for excess costs of educating children with convulsive seizures who "cannot profitably or safely be educated by the usual methods of instruction in the public schools," granting \$200 per pupil.<sup>1</sup>

Whether the child is receiving regular or special class instruction, or home teaching, provision should be made for referral of all cases to a physician or clinic. This involves the sometimes difficult task of interpreting the situation to the parents and securing their co-operation, and necessitates the active and continuous service of a school nurse or public health nurse in follow-up care. It is also important that the child's problems be interpreted to his teachers and fellow pupils so that he may have their acceptance and sympathetic understanding. Although the school does

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<sup>1</sup> Elise H. Martens, *State Supervisory Programs for the Education of Exceptional Children*, Bull. 1940, No. 6, Monograph No. 10, Office of Education, Federal Security Agency (Washington: Gov't Printing Office, 1941), p. 43.

not assume responsibility for treatment, it could play a guiding role in the integration of services of the school physician, public health nurse, family physician, and parents. This would help to prevent the tragic loss resulting from the withdrawal of these children from school, leaving them to drift aimlessly and untrained into a fruitless, dependent existence.

The mental health aspects of the problem of convulsive seizures should receive particular attention, to avoid the social isolation and intellectual stagnation which so often result. In this regard, psychiatric care and social service study are indispensable. The fear, uncertainty and anxiety of those handling a child so handicapped are easily transmitted to him, and chances of recovery are seriously jeopardized by over-solicitude and over-protection. The child guidance clinic should have a guiding role with the school in conducting this phase of the program.

For those who must be excluded from regular classes but can profit by individual instruction, various adaptations should be made within the framework of the educational system. The following are plans which have been put into operation elsewhere in the United States.

1) *Combination of medical, educational, and social planning.* This is a special school plan which is feasible only for the more thickly populated centers. Detroit, which is the only city in the United States which has developed a special school for children with convulsive seizures, opened White Special School in 1934<sup>1</sup> as a part-time boarding school giving full care to the pupils five days a week, for children whose seizures occurred during school hours. The boarding-care aspects were later eliminated and transporta-

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<sup>1</sup> *Education of the Handicapped in Detroit Public Schools* (Detroit: Board of Education, 1937), pp. 37-39.

tion provided for all in attendance. Each child receives the benefit of intensive study and individual supervision and therapy, through the cooperation of the medical college of Wayne University. Once a week a clinic is conducted for examination and diagnosis of new "candidates," referred by the social service department of the Psychological Clinic. Each child is re-examined regularly. The curriculum is flexible, with particular stress being laid on vocational guidance and training. The Department of Special Education assumes responsibility for the educational, vocational, and social-adjustment phases of the program. The program is financed through state aid, which is given in amounts proportionate to that given for blind, deaf, and crippled children.

This plan was designed for the care of the limited number of children who did not fit into a program of home care and regular classwork in school, and does not meet the needs of the much larger group whose problems must be dealt with out in the community.

2) *Assignment to classes for the handicapped.* This plan is used in Los Angeles, where children whose seizures are frequent or severe are referred to schools for handicapped children.<sup>1</sup> Special buses are provided by the Board of Education. The children are not segregated, except for reason of mental incapacity, and are given the advantages of full academic training, occupational training, and vocational guidance. A school nurse and physician are on duty in these schools.

3) *Home teaching.* In New York and San Francisco children excluded from classes because of seizures are assigned to home teachers, after a clinical examination by physicians and a psy-

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<sup>1</sup> Marion F. Mullin, "Educational Facilities for Children with Convulsive Seizures," Master's Field Study, Department of Social Service Administration, University of Chicago, 1943, p. 24.



chologist. The criteria for exclusion are repeated seizures in school, severe seizures, mental deficiency, degree of interference with classroom routine, danger of injury to others, difficulty in handling during an attack, and time attacks occur (morning and afternoon)<sup>1</sup> Those with an I.Q. below 75 are sometimes placed in ungraded classes. Buffalo, New York, conducts a special class for epileptic children. The great disadvantage to the child in home teaching is exclusion from normal group activity and isolation of the child.

4) *Custodial care.* For children who are in need of full-time custodial care for intensive medical therapy, or because home conditions are unfavorable, special institutional care is needed. This is best exemplified by the State Demonstration and Practice School at Sonyea, Geneseo State Normal of Geneseo, New York, one of the few special institutions for persons with convulsive disorders in the United States. Children with I.Q.'s above 50 are admitted and placed in groups according to social maturity, the age range being from five to sixteen years. Academic work is minimized, most of the stress being laid on personal hygiene, handicrafts and non-reading activities.<sup>2</sup> Classes are held from kindergarten through eighth grade.

**Vocational guidance, training and placement**  
The vocational outlook for this handicapped group is indeed restricted, since occupations must be chosen which have few physical or social hazards. Therefore, there is special need for occupational guidance and training, to help maintain morale, and so far as possible provide a means of earning a living com-

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<sup>1</sup> Frederick L. Patry, "The Epileptic School Child," *N. Y. Jour. Med.*, 37 (September, 1937), 1554.

<sup>2</sup> Helen R. Braem, "Education and the Epileptic," *Jour. Exceptional Children*, VII (May, 1941), 316-20.

patible with the interests, abilities, and inclinations of the individual. Especially must they be trained to perform tasks which give a sense of accomplishment and social usefulness. The sheltered workshop, where they may work without fear of discharge for physical condition, is greatly needed. One of the greatest drawbacks in employability of those subject to seizures is the employer-liability clause in workmen's compensation laws, making the employer liable for injuries sustained during work. Occupations must be avoided which call for working at a height, using heavy machinery involving co-operation with others, and driving vehicles. Those occupations which are most favorable are farm work, clerical or library work, horticulture, animal husbandry, music, writing, drafting, painting, and domestic service. Professionally trained persons such as doctors, teachers, lawyers, and ministers, may find useful and successful careers in branches of their fields which do not demand frequent public appearances before groups of people.

Thus, the chief problem is the placement program, which would call for broad public educational activities, and a co-ordinated program of the employment agencies and Division for Vocational Rehabilitation.

**Public education** As Schou has stated, "So long as people believe epilepsy incurable, just so long will people avoid treatment."<sup>1</sup> For many reasons, an extensive program of public interpretation and education should comprise a major phase of any state program. Tuberculosis, cancer, and the venereal diseases once occupied the place in the public mind now held by the convulsive disorders, and it was only through persistent, long-range educational programs

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<sup>1</sup> Schou, "Institutional Care, etc.," *op. cit.*, p. 257.

that the popular fear, superstition, and apathy surrounding them was broken down sufficiently to permit effective treatment programs to be established. The public must be informed that in some cases complete cessation of seizures can be achieved, in others they can be fully controlled with continued medication, and in still others, marked modification can be accomplished. There will always be a number of cases in which little can be done, but in a majority, those suffering from the disorder can find relief and become happy and socially useful persons.

Aside from development of public attitudes which will maintain rather than destroy morale, and promote rather than undermine mental health, there is a very real need to create conditions wherein persons subject to seizures will seek and find competent medical services. Treatment of these disorders has been termed the "happy hunting ground of the quack."<sup>1</sup> Dangerous mail-order prescriptions and patent remedies for the epileptics form one of the most lucrative of all sources for medical quackery. This exploitation, made possible by the secrecy and taboo associated with the disorders, means that the patient not only does not secure proper medical attention, but pays exorbitant amounts for what he does receive.<sup>2</sup> And society pays heavily for its prejudice and ignorance in this regard.

**Financing and costs** In the main, the program should be state-financed, utilizing federal aid and private resources wherever possible. State aid should be made available for health services, maternal aid, and

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<sup>1</sup> Muskens, *op. cit.*

<sup>2</sup> A report of the American Medical Association indicates that phenobarbital, chief ingredient of such patent remedies, costs the average patient \$2.75 per year through prescription, but \$50.00 a year by mail-order. (See *Epilepsy Cures and Treatments*, American Medical Association, 535 No. Dearborn St., Chicago.)

aid to indigent patients. Provisions should be made for patients who are able to do so, to pay full cost for medical care. State aid is especially necessary in transportation costs to clinic school, and hospital centers.



## FACILITIES IN ILLINOIS

Illinois, in common with other states in the Union, has met the problem of the convulsive disorders with gross neglect.

Dixon State Hospital was established as a colony by an Act of the General Assembly approved on May 27, 1913, providing for the treatment and instruction of inmates.<sup>1</sup> A year later, the Director of the Department of Public Welfare permitted admission of feeble-minded patients, in view of the fact that the state was faced with a waiting list of over 1,000 at the Lincoln State School and Colony, and only 100 admissions of persons with seizures had been made at Dixon.<sup>2</sup> Within the limitations of overcrowded facilities, and an overburdened staff, modern medical and educational therapy is provided, but the tendency to commit only deteriorated persons, and the reluctance of parents to permit their children to be sent to an institution whose main function is care of the feeble-minded has prejudiced the original intention of the law establishing Dixon State Hospital.

The Mary E. Pogue School at Wheaton and the Beverly Farm Home and School at Godfrey are the only private schools in Illinois which have reported to the Commission that they have diagnostic and treatment services for children with seizures. From 1913 to 1940, the Chicago Board of Education maintained a special class for children subject to seizures, averaging eighteen in enrollment. For "reasons of expediency,"

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<sup>1</sup> Laws of Illinois, 1913, p. 133.

<sup>2</sup> Warren G. Murray, M.D., *A Handbook of Information, Dixon State Hospital, 1935*, p. 11.

these classes were discontinued in the school year 1941-42 and have not been re-instituted. The problem of transportation was apparently one of the chief stumbling blocks in the program.

In Chicago, diagnostic services are available chiefly through the following hospitals: Children's Memorial Hospital, Montgomery Ward Clinics of Northwestern University, Research and Educational Hospitals of the University of Illinois, and the University of Chicago Clinics. Among outpatient clinics treating children having seizures are Children's Memorial Hospital, Cook County Hospital, the Mandel Clinic of Michael Reese Hospital, Mercy Hospital, Mt. Sinai Hospital, Montgomery Ward Clinics, Presbyterian Hospital, Provident Hospital, Research and Educational Hospitals, St. Luke's Hospital, and the University of Chicago Clinics.

Medical and home nursing services are available in Chicago and Cook County through the county physicians' service, and the Cook County Public Health Unit. Two private agencies offering auxiliary services are the Visiting Nurse Association and the Infant Welfare Society. Several health clinics are maintained by the Chicago Board of Health.

Downstate hospitals reporting diagnostic and treatment services for children with convulsive disorders are Norbury Sanatorium, Jacksonville; Silver Cross Hospital, Joliet; and Victory Memorial Hospital, Waukegan.

## UNMET NEEDS IN ILLINOIS

Thousands of dollars can be saved by the community annually through an adequate program for care of children with convulsive seizures. Illinois needs to make available and known to the public a co-ordinated plan of identification of cases, diagnosis and treatment. This should include nursing homes for treatable cases, and a system of aftercare for those living in their own or foster homes. Such aftercare would provide a means of supervising medical treatment, and offering guidance as to vocation and social adjustment. The need for this broader use of medical social service has long been recognized by many authorities:

The treatment of the epileptic, apart from the control of fits, is a matter of attending to the mental health both of the patient and his family. . . . The hospital doctor requires the help of the mental welfare worker as surely as the medical officer of health and the school medical officer require that of the health visitor and the school nurse.<sup>1</sup>

If one were to consider the time and energy, and the personnel involved, in an effort to extend medical responsibility to all the conceivable economic, sociological, and educational aspects of the problem of epilepsy, it should be easy to see why the physician taking care of an epileptic child must by necessity limit his endeavors [to the immediate medical problem.]<sup>2</sup>

Special educational services are needed by large numbers of epileptic children who cannot benefit from or are not allowed to participate in the regular school program. The General Assembly has provided for

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<sup>1</sup> Ralph H. Crowley, "The Social Care of the Epileptic," *The Lancet*, 234 (January, 1938), p. 61.

<sup>2</sup> *Epileptic Children*, p. 44.

State aid in financing the costs of these services, but it remains for each community to recognize its local needs and initiate a plan for answering them. Closely coordinated with the school and medical program there is needed a program of vocational guidance, training, and placement, and a system of sheltered workshops.

A campaign of public enlightenment is needed to educate both the general public and those subject to seizures as to the nature of the disorder, the fact that it can be remedied, and what resources are available.

And, finally, the State needs to underwrite research in the field, so that a continuing program of research, closely linked with preventive effort, may be maintained to bring the full resources of the State to the aid of these thousands of long-neglected handicapped children.



## RECOMMENDATIONS

It is recommended, therefore:

1) That an exhaustive study and statistical analysis of the problem of the epilepsies be made on a state-wide basis, to determine the extent of the problem, what treatment resources are available, and how they are being used.

2) That a system of case-finding and reporting be established.

3) That special educational facilities be made available in the form of home teaching, hospital instruction, and special classes, with transportation provided where indicated.

4) That the Chicago Board of Education be urged to establish special school facilities making use of existing resources.

5) That there be required in the curricula of teacher-training institutions courses dealing with understanding of behavior problems of children, and understanding and handling of the child who has seizures.

6) That the public health service of the State establish facilities for care of extra-mural patients, based upon full use of available clinic and hospital resources, and development of further facilities where needed.

7) That adequate psychiatric and medical social work follow-up care be facilitated through interested state departments.

8) That fullest use be made of provisions of the maternal and child health aspect of the Social Security Act and the resources of the Aid to Depend-

ent Children Program, the Division of Child Welfare, and other state-wide social services, in promoting social welfare of this group of handicapped.

9) That the work of the Division of Vocational Rehabilitation be expanded to serve the special needs of this group for vocational guidance, training, and placement, with special attention given to the establishment of a system of sheltered workshops.

10) That the Workmen's Compensation Law be amended, to shift injury liability from the employer to the State Treasurer's Fund, in cases involving persons with convulsive seizures.

11) That preventive efforts be advanced through public education by the Department of Public Welfare and Department of Public Health with respect to means for reduction of incidence of infectious diseases which lead to damage of the central nervous system; and promotion of better obstetrical practices, to reduce the number of birth injuries.

12) That a program of public education be promoted with the aid of newspapers, magazines and other distributed literature, the radio, and public meetings, to insure early reporting and treatment of cases; to advise against resorting to use of mail-order remedies; and to enlighten the general public with respect to the nature of the problem and the urgent need for dealing with it.

13) That a continuing program of research be carried on with the sponsorship and aid of the State.

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JANE BULL

*Informational Representative*

EVELINE E. BLUMENTHAL

*Social Research Analyst*

VIRGINIA D. BONNICI

*Librarian*

HELEN A. EGGERS

*Secretary*












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